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RESEARCH

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Qualidade de vida de cuidadores familiares de pessoas com Síndrome de Down

Quality of life of family caregivers of people with Down Syndrome

Calidad de vida de cuidadores familiares de personas con Síndrome de Down

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ABSTRACT

Objective: to analyze the perception of parents/caregivers of people with Down syndrome on quality of life. **Methods**: It is a qualitative study, which used for data collection semi-structured interviews with 10 caregiver parents of people with Down syndrome. To analyze the data, we used the content analysis technique. **Results**: It was observed that caregivers are mothers over the age of 30, who declared themselves as racially mixed (Pardo in Portuguese), live with a partner, practice some type of physical activity and attend any educational institution. Moreover, they had as main occupation the caregiver role. Caregivers reported that access to leisure; health; family relationships; general welfare; Material and rights were the factors that influence the quality of life. **Conclusion**: it was concluded that caregiver parents of people with Down syndrome had different views on the quality of life.

Descriptors: caregivers; quality of life; down syndrome.

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RESUMO

Objetivo: analisar a percepção de pais/cuidadores de pessoas com Síndrome de Down sobre qualidade de vida. **Métodos:** trata-se de um estudo qualitativo, que utilizou para coleta de dados a entrevista semiestruturada com 10 pais cuidadores de pessoas com Síndrome de Down. Para analisar os dados, recorreu-se a Técnica de Análise de Conteúdo. **Resultados:** observou-se que, os cuidadores são mães com idade acima de 30 anos, que se autodeclararam pardas, conviviam com um companheiro, praticavam algum tipo de atividade física e frequentaram alguma instituição de ensino. Além disso, possuíam como ocupação principal a função de cuidador. Os cuidadores relataram que o acesso ao lazer; à saúde; relações familiares; bem estar geral; material e direitos seriam os fatores que influenciam na qualidade de vida. **Conclusão:** concluiu-se que os pais cuidadores de pessoas com Síndrome de Down apresentaram diferentes concepções sobre a qualidade de vida.

Descritores: cuidadores; qualidade de vida; síndrome de down.

RESUMEN

Objetivo: analizar la percepción de los padres / cuidadores de personas con síndrome de Down en la calidad de vida. **Métodos:** se trata de un estudio cualitativo, que utilizó la recolección de datos de entrevistas semi-estructuradas con 10 padres cuidadores de personas con síndrome de Down. Para analizar los datos, se utilizó la técnica de análisis de contenido. **Resultados:** se observó que los cuidadores son mujeres mayores de 30, que se declararon marrón, que viven con un compañero, practicaban algún tipo de actividad física y asistieron a cualquier institución educativa. Por otra parte, tenía como ocupación principal rol de cuidador. Los médicos informaron que el acceso al ocio; la salud; las relaciones familiares; bienestar general; Material y derechos fueron los factores que influyen en la calidad de vida. **Conclusión:** se concluyó que los cuidadores padres de personas con síndrome de Down tenían diferentes opiniones sobre la calidad de vida.

Descriptores: los médicos; la calidad de vida; el síndrome de down.

INTRODUCTION

The Down Syndrome (DS) is a genetic disorder discovered for over a century and it is little-known because it affects from 1/600 to 1/1000 live births around the world.[1] In Brazil, data from the National Health System (SUS) showed the birth of 3,035,096 children in 2005, so it is estimated that in that year about 5,058 people were born with DS in the country, comprising the ratio of 1 every 700 births.[2]

In this perspective, DS - as the earliest clinical condition associated with mental retardation and the most common genetic cause of disability in the development of all the other syndromes, it can be said that there is a much larger number than what was estimated for people with DS around the country.[1]

Some studies have indicated that the comorbidities related to DS are the main causes of an existing burden on caregivers. These diseases that affect people with Down syndrome, in most cases, affect both the quality of life (QoL) and health in many ways, increasing the degree of dependence of these individuals and therefore also affecting QoL and caregivers' health.[3-4]

Given the above, it is common that there are two aspects in relation to the conduct of family caregivers: sense of life in carrying out the activities of caring, accepting their caring role; not accepting this condition and taking this function as a wear, that makes it impossible to carry out their personal wishes.[5] Anyway, in both cases there is a physical and emotional burden just because they are parents, and so, they are conditioned to function of caregiver, in need of psychological support and the availability of information provided by health professionals.

Caregivers are those people who assume the responsibility of caring, support, or watch any need for careful person, aimed at improving their conditions of health.[6] The role of the main caregiver of the DS person is such important in supporting and in assistance to people in need of special care, as well as their permanent integration in society, preventing and inhibiting situations and actions of exclusion.

In the case of DS this responsibility is usually the mother's.[7] In this sense, these caregivers undergo a physical and emotional burden, considering the strong emotional bonds that they usually develop with their children from the period of pregnancy. It is common in early DS discovery, family and especially his mother are not prepared to assume the responsibilities required and so, instead of taking care, they need care.

According to the World Health Organization, Quality of Life (QOL) is defined as the perception that the individual has about his position in life with respect to culture and value systems in which they live and in relation to their goals, expectations, standards and concerns, and it is therefore subjective and multidimensional that manifests itself in different areas.[8]

METHODS

It is a qualitative study with a descriptive design; qualitative studies are used when it is necessary to recognize the complex reality that requires different and integrated knowledge.[9]

The study had the locus one of the units of the Association of Parents of Exceptional (APAE), in the municipality of Jequié, Bahia. After identifying the number of individuals with Down syndrome and their parents respectively, we selected for the study 10 from the 27 caregivers. Caregivers who were not a parent of persons with Down syndrome did not participate in the study, and accordingly we worked out with the total population of the institution.

A semi-structured interview was used for data collection, having two blocks: bio-socio-demographic characterization and specific themes on QoL. For data analysis, we used the content analysis technique, when the evocations were organized and grouped into categories, as classified into categories it allows for greater clarity when analyzing the

elements present in a statement, thus it is possible to know the true nature of the content manipulated.[10]

At the end of each analysis unit is arranged an alphanumeric element which identifies the subject order of interviews, for example, to the informant 1 we used the C1 encoding, where "C" represents the caregiver word and "1" identifies the subject.

Seeking to comply with Resolution 466/2012 of the National Health Council, which addresses research on human beings, supported on ethical and legal aspects, the research was approved by the Ethics Committee of the UESB (CEP/UESB) under number CAAE 11057912.5.0000.0055. All participants have signed the Informed Consent (IC).

RESULTS

Clinical and epidemiological profile of the parents/caregivers of people with Down Syndrome

This study concentrates information on the perception of parents/caregivers of people with Down syndrome about their QOL, assisting in targeting more effective strategies in promoting health and improving the QOL of this population.

Disclosure of some socio-demographic characteristics was presented in Table 01 of parents/caregivers, although it is not purpose of this research, it is seen as a necessary resource, since it can subsidize the understanding of the discussions proposed here.

Table 01: general Distribution of socio-demographic variables of the parents/caregivers of people with DS. Jequié/BA, Brazil, in 2014.

Variable	Condition	Frequency	
		Nº	%
Gender	Male	2	20
	Female	8	80
Age	25-29	3	30
	30-35	3	30
	36 or older	4	40
Color	White	2	20
	Black	1	10
	Parda (racially mixed)	7	70
Education	Elementary School	5	50
	High school	4	40
	Higher education	1	10
Main occupation	Caregiver	7	70
	Other	3	30
Marital status	Married	4	40
	Single	3	30
	Common-law marriage	3	30
Age of child with DS	0 to 5 years-old	5	50
	6 to 12 years-old	3	30
	12 or older	2	20
Number of children	1	4	40
	2 or more	6	60
Health condition	There's health problem	7	70
	No health problem	3	30
DCNT	Yes	3	30
	No	7	70
Physical activity and leisure	Light	3	30
	moderate	3	30
	Heavy	0	0
	Don't participate/ practice	4	40
Sufficient nutrition	Yes	10	100
	No	0	0

Contextualizing the study population, it is notable that most of them are mothers (80%), which have already exceeded 30 years-old (70%), whose main occupation is caregiver role (70%), living with a partner (70%), who claim to be parda (70%), practicing some kind of physical activity and leisure (60%), which has some health problem (70%) and all have attended any educational institution.

The QoL of life of parents/caregivers of people with Down syndrome refers to how the caregiver feels and behaves, in the context of culture and value system in which they live, in the face of caring responsibilities, support, or watch some need for careful person in order to improve their health.

It was found five relevant categories of analysis for the study: access to leisure, access to health, Family, General well-being and material well-being and rights.

Cathegory I – Acess to leisure (AL)

This category comprises the QoL from the element access to leisure. Access to leisure refers to the time allotted for conducting activities that seek pleasure as traveling, playing sports, going to events, going to clubs, access to digital social networks and others.

In this perspective, the meanings of access to leisure by parents/caregivers are arranged in a plan to be achieved, since there are limiting factors as can be seen in the following units of analysis:

[...] Quality of life is traveling, doing activities, doing something(C1).

[...] We work a lot and often we do not have time for ourselves and for our children (C2).

[...] Quality of life is sport, leisure (C3).

[...] I have no time for anything after my son [...] I used to go the gym, to work, to get out more [...] nowadays I only access the social networking sites (C7).

[...] Quality of life is to have condition to travel more (C9).

Cathegory II – Acess to health (AH)

This category consists of the perception of health condition related to the QoL and public health issues, they are expressed as follows:

[...] Quality of life is more doctors [...] that actually there are more doctors for everyone (C1).

[...] Quality of life is good health (C3).

[...] The quality of life, if it is in terms of health, we do not have much opportunity in health care (C4).

Cathegory III – Family (FA)

The conception of QoL related to the family, which includes the well-being within the family, is part of the central ideas laid out in this category. Given the above, it is clear that family relationships, to some extent, influence the QOL of their members as well as the interpretation of the experience of each family member.

This category consists of the following units of analysis.

[...] Quality of life is to take time for your child (C1).

[...] To give affection to their children (C3).

[...] To have support from family, friends… (C4).

[...] I work a lot and I do not have time [...] our children

[...] I have two children and I have to divide my time (C5).

Cathegory IV – General well-being (GWB)

Physical activity, eating habits and risk behaviors comprise aspects of this category, which can be understood as the satisfaction with life and yourself.

The analysis units are arranged as follows.

[...] Quality of life is [...] to have an active life (C2).

[...] to improve my nutrition would be improving my quality of life (C3).

[...] To have quality of life is [...] to play sports, do not smoke, do not drink alcohol (C6).

[...] To do physical activity three times a week (C7).

[...] I want to do physical activity (C9).

[...] Quality of life is to take care of (C10).

Cathegory V – Material well-being and Rights (MWBR)

This category includes QOL from the dimension of work and is also associated to parents'/caregivers' rights issue.

[...] We rush (work) a lot to try to have something (C3).

[...] to have a more balanced financial life would help to improve my quality of life (C5).

[...] Quality of life is to have a good income (C6).

[...] Quality of life is [...] to have jobs (C7).

[...] While working was something else [...] I have to take care of my son and the money has decreased considerably (C8).

DISCUSSION

The proposed study on QOL in relation to the area of health sciences has been intensified in our times and raised research methodological and conceptual review, in addition to reflections, discussions, debates and research in several areas of health and with different populations.[11-2]

Parents recognize that access to leisure can provide improvements in their quality of life. There are many definitions for leisure, one of the most common and substantially comprises a dichotomy between the terms leisure and work, that is, the use of free time (time off work) to carry out activities in pursuit of pleasure. However, leisure concept is subjective in that it is the work to leisure can be an individual to another. In a broader and more elaborate way, some authors also define leisure in this perspective:

[...] It is the set of individual or collective activities for the satisfaction of a number of interests in terms of staff training, definition of activities and personal improvement "held at the time released from the obligations imposed by the professional work and other social responsibilities". [13]

The possibilities of access to leisure, from the excluded and low-income population in Brazil, are increasingly restricts.[13] Access to recreation is associated with improvement in QoL, however, there are still few public policies aimed at promoting leisure for the population.

In a recent study aiming to identify the constraints and conflicts faced in everyday life for families of children with chronic illness. The results showed that there is impairment in mental dimension of these families.[14]

[...] The financial imbalance as a result of the expenses and charges of chronic illness can lead to reduction or interruption of leisure time needed to restore the energies

and strengthen families, making it difficult to overcome the drawbacks arising from the walk, leaving them more vulnerable psycollogically.[14]

Access to leisure in low-income households is restricted to sports, public squares occupation and the new phenomenon of networks sociais.[13] Given the above, it is observed that 60% of respondents participate in regular leisure activities. However, the desire for more leisure time is present and at the same time is a limiting factor for the QoL of parents/caregivers as available free time is scarce because of the occupations with the child.

Access to health implies a close relationship between the term QoL and health.[15] In the second category, it is evident that QOL suffers interference by the absence of aggravating to health and the it is influenced by the availability of health services. On this last point, a major lack of parents is perceived, since they are caregivers and need to have greater support from health professionals.

About this, studies argue that parents feel insecure and helpless as caregivers because of the limited information that they have on the DS. So there is a need for greater attention on the part of health professionals, for those families who are in situation of vulnerability.[16]

It is noticed that the QOL in family dimension is seen by parents/caregivers as a need to be closer to their children, this is due to the greater presence of responsibilities as a caregiver since the child requires special attention by having a chronic injury such as DS. Thus, some authors define family as "a complex and dynamic system, being influenced by historical, social and cultural environment that they've experienced".[17]

Regarding the number of children, 60% of participants of the sample have more than one child in the household. In this perspective, QOL of parents/caregivers is reduced when there is the presence of more children in the household beyond the assisted child.18 The care for the child with Down syndrome require time and responsibilities that in many families are hard to reconcile. Parents feel a greater need for being close to their child with Down syndrome, however, the majority share attention with other children and with other clinical responsibilities of the child affected, which can lead to frustrations.

Another point is the presence of a companion at home, 70% of parents claim to have the presence of a companion in the household. The presence of a companion lessen the burden to the primary caregiver of the family, diminished physical and mental strain to be a division of responsibilities that from the perspective of the functional family system would bring familiar benefits.[17] However, for households with members who have chronic diseases is common for one member in the family assume much of the responsibility.

However it is necessary to be a follow up of these families by professionals in order to get the information needed to build a good relationship in the family unit, contributing to the relationship between parents and children with Down syndrome is in addition to the necessary clinical care.

Reports from parents/caregivers have demonstrated that QoL is commonly associated with physical exercises or physical activity (PA) and food. In this perspective, they understand the need for some kind of physical activity for health maintenance and improvement of QoL through leisure, in addition to the need for improvements in power.

The vast scientific literature reveals that there is a positive relationship between physical activity and quality of life. In this perspective, in a review study that seeks to understand the association between PA and QoL in adults, it indicates that the PA is commonly understood by two dimensions of QOL: health and leisure. PA is perceived as a means for a possible maintenance of 'good status' of health. Therefore, to perform some PA is also a way to occupy the free time.[19]

Another crucial factor in this category is the eating habits and other risk behaviors. "Food is one of the most important modifiable factors that could mitigate the risk of chronic diseases, and contribute in improving the quality of life of individuals, it needs to be understood as a priority for action in the context of public health"[12] Given the above 100% of parents concerns to feed sufficiently, which does not mean fedding properly.

The Pan American Health Organization suggests that behaviors such as eating fruits and vegetables rather than fats, daily physical activity, maintaining a normal body weight and not smoking cause rapid changes in risk factors related to DCNT.[20] In this perspective, we realize that healthy eating is essential in improving the QOL of parents/caregivers, but there is a need to have a professional monitoring in order to provide the necessary information to the changes in the lifestyle of these people.

There are still testimonials from caregiver parents who are largely directed to the element "work", for the opportunity to work becomes a way to supplement the family income and ensure a financial balance within the family. It is noticed, also, that the opportunity to work outside the home would be a way of getting out of the rut often grueling and stressful for caregivers.

The fact that being a caregiver of an individual with DS creates a financial burden that the care result in higher costs due to the need to pay special attention to health, education and leisure.[7] Therefore, access to private health services is restricted, which generates frustration as parents also cannot develop work activities paid due to a reduction of free time, thus reducing the family budget.

CONCLUSION

The promotion of self-care for parents of people with Down syndrome requires first identifying the factors that influence the quality of life of these people, which is based on different conceptions among people with different economic, cultural and social conditions. In this sense,

health professionals who work with individuals with Down Syndrome should be attentive to caring for the care givers, looking for ways to mitigate the physical and emotional distress caused by the performance of daily activities and promoting the quality of life of parents/caregivers within the possibilities.

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